



QUALITY OF PUBLIC HEALTH INFORMATION: LESSONS FROM THE FIELD

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INTRODUCTION

Access to high-quality public health information is an important ingredient in the development of effective public health policies and programs. While the political environment, economic considerations, social conditions, and values undoubtedly are key components that influence decision making, there is an often-overlooked place, and need, for valid and reliable public health information. Many important health policy decisions in US history have been made that place a high reliance on data and information.¹

It is simple enough to state the importance of high-quality public health information. It is much more difficult, however, to ensure that information is used effectively for developing, implementing, and evaluating public health policies and programs. Reaching consensus over what constitutes quality information in public health practice has been difficult. Even when there may be consensus, finding the high-quality information, determining what to use, and knowing how to use it pose a different set of challenges. Knowing where information gaps are present and knowing also how to fill these gaps through better use of existing data or through development of completely new data sets are even more difficult.

This paper addresses challenges faced today in the gathering, analysis, and ultimate use of high-quality public health information. Practical examples concerning the use of data and information are discussed, and potential ways to address some of the quality issues are explored. By no means is this meant to constitute an exhaustive list of examples, problems, and solutions. Rather, this

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is to serve as a stepping stone for better understanding the current state of public health information and areas in which improvements can be made.

**HIGH-QUALITY PUBLIC HEALTH INFORMATION:
SOME BASIC PRINCIPLES**

Issues concerning the use of quality public health information can be discussed in many different ways. For the purposes of this paper, three basic principles, or maxims, are presented, and each is followed by examples and lessons learned from the field of public health practice.

PRINCIPLE 1

Accept reality. In a perfect world, we might expect perfect information, but in our imperfect world we must learn to accept and use imperfect information.

Communicable disease reporting systems provide essential information for helping to determine the health status of communities. These systems are used to monitor and prevent communicable diseases and serve as early warning systems for emerging problems. Communicable disease reporting systems also enable the public health community to respond to unexpected, or unanticipated, occurrences of disease.

These systems are not perfect. There are problems of under-reporting and the inconsistent application of definitions. The rigor applied to diagnosing communicable diseases and ultimately reporting their incidence may vary tremendously within and across jurisdictions. Similarly, while the Centers for Disease Control and Prevention have been effective in establishing and disseminating definitions of communicable diseases, the interpretation of these definitions is not necessarily consistent. Even with these and other imperfections, communicable disease reporting systems are recognized as playing a critical role in protecting the public's health.

An example of incomplete, or inconsistent, reporting is for primary syphilis. Some states see this as a key element of their reporting systems, while others may give this less emphasis. Thus, the level of rigor applied to reporting of primary syphilis will vary among states, belying the actual incidence of the disease. Definitional issues come into play as well. For example, if a pregnant woman diagnosed with syphilis is treated before the birth of the child, this may or may not be categorized as congenital syphilis, depending on the state's definition. Last, incomplete data gathering can occur even under systems designed to ensure the opposite. Some jurisdictions require public health nurses to confirm cases of primary syphilis in order for them to be "officially" reported. While this might seem to create greater certainty in the universal application of

definitions, in reality, if there is a shortage of available public health nurses, actual cases of primary syphilis may go unconfirmed and unreported. There may be the illusion of completeness and comparability of communicable disease data among and across jurisdictions, but this is not necessarily the reality.

Recognition of the imperfections of our communicable disease reporting systems, and how to compensate for these imperfections, has contributed to the proper use of these systems as vital sources of public health information. The systems that are in place today effectively capture the "big problems." The public health practice community does a stellar job of diagnosing and tracking emerging epidemics. These systems also have performed well in tracking disease rates and trends within states and in individual communities. While there are difficulties in comparing rates across states, there is the ability to compare trends. Even with under-reporting and definitional problems, there is a tremendous value in our nation's current communicable disease reporting systems. We have learned to use this imperfect set of information effectively.

While we have learned how to live with the imperfections of the communicable disease reporting systems, the same cannot be said for public health infrastructure reporting systems. From 1970 to 1994, there existed a voluntary reporting system that annually collected infrastructure data from virtually every state health department in the country. Reporting consistently was near 100% each year. This information system collected data on state health agency organizational characteristics and responsibilities, expenditures and funding sources, services and activities, workforce, and funds provided to local health departments. This was the primary source of information on the services, activities, and resources of our nation's state health agencies, and it enabled policymakers, researchers, and others at the federal, state, and local levels to compare state structures, per capita expenditures, types of services and programs, and 10-year trends. Users and providers of the data were involved in the system's design and refinement through the years.

However, there were problems with the state infrastructure reporting system. The system did not include public health programs from state agencies other than the health department. With frequent changes in organization structures at the state level, data collection was difficult as programs shifted from one agency to another and often back again. The public health systems and structures from state to state differed so dramatically that this limited the ability to compare data across states. Also, definitions were subject to different interpretations from state to state and sometimes from year to year.

Even with the limitations of the state infrastructure reporting system, there

were many important uses. Similar to the communicable disease reporting systems, this system was able to pick up "big swings." The data from the system provided important information on infrastructure changes, such as increases or decreases in investments in public health programs, movement of programs from one agency to another, and reorganization and structural changes in state health agencies. It was excellent for tracking trends within states and for comparing trends across states. Some of the same problems and attributes of the state infrastructure reporting system have been experienced by the communicable disease reporting systems. However, the infrastructure reporting system was unable to survive its imperfections.

Since this system's demise in 1994, much progress has been made on refinement of definitions to reduce variability of interpretation and in the development of tools to ensure greater reliability of the data.² With no ongoing system in place to see that data are collected, however, a major investment likely is required to develop a new system with a similar level of state commitment and reporting as existed in the past. In an age of major changes to our health care and public health systems, it would have been preferable to have imperfect information rather than none. While we may be able to track disease, we are unable to track the infrastructure necessary for preventing and combating disease.

PRINCIPLE 2

Information already exists that can be used to improve the performance of the public health system. However, the trick is to find it, to determine what to use, and to know how to use it.

Although well-established authoritative sources of quality public health information may not exist, there certainly are excellent sources of particular types of information. Locating these sources, and knowing how to access and use the information, can be difficult.

Some state health departments go to great lengths to provide good-quality health status and health status-related information to their local jurisdictions. The Missouri Department of Health, for example, gathers data from a multitude of sources and produces analyses to provide a picture of the health status of each of its counties. Data on demographics, education, socioeconomic status, risk behaviors, morbidity, mortality, and many other areas make up these profiles. Supplemented with good, qualitative information from communities, one can develop fairly complete assessments of community health needs and assets.

While the county health departments in Missouri know how to access the information provided by the state health department and, over the years, have

learned more about how to use this information for improving community health, there are many others in Missouri who could benefit from this information, but do not know it exists. When querying mental health agencies in the state last year about this information source, some were surprised of its existence, while others were unaware that the data had relevance to their own needs. This poses two challenges: (1) expanding access to such information among those who can use it, and (2) demonstrating the utility of the information to public health agencies and community organizations that may not realize its relevance. Ignoring these challenges leaves those making public health policy and program decisions to utilize sources of lesser-quality information.

Missouri, in many ways, is ahead of other states because it already has a high-quality information source. Far more difficult than turning state data into useful information about community health (although the difficulty of doing this should not be underestimated) is developing valid and reliable information that can provide guidance on what constitutes effective interventions and strategies for improving community health. For years, there has been little, if any, good-quality information that could be used for improving the interventions and strategies employed by the public health community.

In 1994, the Council on Linkages Between Academia and Public Health Practice (hereinafter, the Council) began an effort to explore the feasibility and desirability of developing science-based guidelines for the practice of public health. While there is no preponderance of randomized, controlled clinical trials in public health, there was the sense in the practice and academic communities that it was possible to find and utilize science for improving practices. At the conclusion of a 1-year effort, it was determined that, through the use of peer-reviewed articles, descriptive studies, program evaluations, expert opinion, and empirical evidence, scientific principles could be used effectively for developing public health practice guidelines.³ While the type of science may differ from what is used to determine, for example, medical efficacy, processes that utilize modified methods of meta-analysis, in combination with expert panels and cost-effectiveness studies (in public health, efficacy frequently must be weighed against cost), make it feasible and desirable to begin developing science-based guidelines in public health.

Today, the US Public Health Service, under the coordination of the Centers for Disease Control and Prevention, is in the process of developing a science-based *Guide to Community Preventive Services* (*Guide* hereinafter). Under the oversight of the 15-member, nonfederal Task Force on Community Preventive Services (Task Force hereinafter), chapters of the *Guide* will address areas of public health practice that are thought to have the greatest influence on reducing mortality

and morbidity. Similar to the Council's 1994 effort, the *Guide* will utilize evidence from a wide variety of sources and recognizes some of the limitations of the scientific evidence base.

Because evidence from randomized controlled trials likely will be less prevalent for many population-based interventions, the Task Force is addressing the need to determine how evidence from published quantitative and qualitative studies, unpublished evidence (e.g., evaluation reports carried out by state health departments), and potentially, expert opinion, will be translated into recommendations for the *Guide to Community Preventive Services*.

There is general discomfort with the descriptive study and the use of social science methods for helping to determine the efficacy of public health interventions and strategies. Questions remain about where the line is drawn between highly quantitative scientific rigor and the conjecture that often accompanies qualitative information. However, without use of such studies and methods, the practice of public health may be destined to continue with little guidance on efficacy. The application of unreasonable, and often inappropriate, scientific standards has hindered our ability for many years to provide guidance for the practicing public health professional.

Based on work of the Council and the Task Force, it is evident that good information exists to better inform the practice of public health. The challenge now is learning how to use this information more effectively.

At times, in public health, we also are faced with the dilemma of having to choose between older, high-quality data that ensure comparability across jurisdictions and communities and newer, less "clean" data, which may lack standardization and comparability. With the newer data, one may be able to gain a better understanding of current conditions in a community, although potentially sacrificing a degree of accuracy because the data may not have been standardized across localities and states. The older data, on the other hand, may provide a more accurate picture, although less timely, as well as allow for comparisons with other communities.

A new initiative of the Health Resources and Services Administration, the Community Health Status Indicators (CHSI) project, illustrates the debate over timeliness and accuracy. Through this initiative, profiles will be developed for every county in the country, providing information on a multitude of health status and health status-related indicators. The intent is for local health departments to have access to current, well-analyzed, and standardized quantitative data that will help them better understand community health. In addition, the CHSI profiles are meant to provide counties with the ability to compare themselves with jurisdictions having similar population characteristics. Such comparisons could enable local health departments to learn from communities that have made

progress toward improving health status and in meeting community health status objectives. This type of information, for each county in the nation, has not been developed previously.

One of the biggest unanswered questions about the CHSI project is whether to use slightly older, higher-quality standardized national data sets, enabling comparisons to be made between jurisdictions, or to use newer, less-standardized (and, in some instances, less-clean) data that can be obtained from individual states. There clearly are trade-offs regardless of the final direction chosen. Ultimately, the decision should be based on how the information is to be used. This is clearly an instance for which determining the final step in information development—how it is to be used—must be decided prior to development of the information. In reality, this is a question that should *always* be asked, and answered, whenever public health information is being developed.

PRINCIPLE 3

Better information is still needed on ways to improve the practice of public health. The key is to define what is needed, to determine where it can be found, and to collect it.

To this point, this paper has focused on access to and use of quality public health information derived, for the most part, from secondary sources. Even recognizing that a great deal of good data and information already exist, there is still a tremendous need for better information on public health practices. There is little quality information on infrastructure and practices that can be used by the public health profession in its efforts to better serve communities. Without having even baseline data on infrastructure and a body of information on “best practices,” practitioners often rely simply on their “best judgment” to determine how our public health system is structured and the types of interventions and strategies that are developed and employed. To the credit of the public health profession, best judgment has served us well for many years. Today, in our highly competitive health care and public health systems, with increasing attention toward measuring performance and demonstrating positive outcomes, it is becoming essential to have excellent information on infrastructure, practices, and performance. This makes the location and creation of new primary public health data and information sources critical to the future practice of public health.

What is it that we know and understand about our nation’s public health infrastructure? In 1916, the American Medical Association expressed its concern about the nature and quality of information on state health departments and stated:

As the reports of the various state boards are not made on a uniform basis, a comparison of their various activities and tabulations of the results secured by their efforts is difficult. It is therefore practically impossible today to summarize the public health work which is being done by the different state boards of health, to compare one with another or to establish any standard by which the relative merits may be determined.

The conditions that existed at the beginning of this century persist as we near the turn of a new century. The recently completed study conducted by the Lewin Group, "Strategies for Obtaining Public Health Infrastructure Data at Federal, State, and Local Levels," describes the continuing and critical need for infrastructure data as well as the current state of this information:

Despite the rapidly changing role of public health and the need for assistance in reconfiguring the public health infrastructure, policy makers, public health professionals, and researchers currently do not have access to comprehensive data on the capacity and functioning of the public health system. This type of information is crucial for evaluating the impact of market-based changes on public health services, examining the cost-effectiveness of public health interventions, and improving the performance of public health agencies.⁶

The study recommends a multipronged approach to developing infrastructure data and information, involving national surveys, case studies, and establishment of a research agenda, at an estimated biennial cost of approximately \$5 million.

Given the history of limited investments in public health infrastructure information systems, the likelihood of complete implementation of a new multimillion-dollar strategy seems slim, at best. However, this report, combined with additional input from public health professionals, policymakers, researchers, and others, can serve as an important impetus to develop priorities for data and information needs. Applying what has been learned from current and previous infrastructure data collection efforts can lead to the gradual implementation of a national strategy for the production of quality infrastructure information.

Not only is there a critical need for high-quality infrastructure information, there is an equally great, and related, need for similar information on best practices. As discussed above, the US Public Health Service has embarked on a multiyear effort to develop a *Guide to Community Preventive Services*. While this impressive effort undoubtedly will produce excellent information to guide practices, it only will address a limited number of public health strategies and interventions. This is due to resource constraints, as well as to the reality that much of the existing information on public health may not meet the evidence criteria established by the Task Force.

As the Task Force continues its work, its efforts also will lead to a systematic investigation, for the first time, of what we do *not* know about the effectiveness of public health interventions and strategies. This will contribute to the identifica-

tion of a research agenda that, if implemented, will foster greater understanding of the effectiveness of a variety of public health practices.

As has been the case with developing quality infrastructure information, there also has been limited interest in developing, and supporting, prevention effectiveness research as it pertains to public health practices. The former Assistant Secretary for Health, Philip R. Lee, stated:

While a significant proportion of the NIH funding for biomedical research is relevant to prevention, the nation's investment in public health research lags behind biomedical and clinical research. Translating knowledge about the causes of disease, injury, and disability into sound prevention programs requires substantial additional understanding of social, behavioral, and environmental health sciences. Further, there is no body of health services research specifically focused on population services.^{7(piii)}

Although there may be promise, with proposed increases in the budget for the National Institutes of Health, the degree to which any increase will be used to fund applied public health research efforts is unknown. Even with new funding for applied public health research, we are years away from conclusive studies that lead to recommendations for improving public health practices. This being the case, we must look for short-term approaches for developing quality information that can provide more immediate guidance on interventions and strategies that appear to work in public health practice.

There are effective approaches for producing quality information on best practices. While not necessarily as rigorous as the methods being used by the Task Force, rigor still can be applied to identifying and describing best practices, and with a smaller investment of resources. How this can be accomplished, and why this is important to do, is discussed in the following example.

In May 1996, public health practitioners and researchers from federal, state, and local levels were brought together to develop an action plan for improving public health information systems, with an eye toward improving the collection, analysis, and use of information for community-based health services.⁸ During the development of this action plan, it became apparent that a great deal is already known about how to improve information systems, but rigor has never been applied to a systematic approach for compiling this information. The two priority recommendations of the report were to:

1) identify and communicate current efforts to successfully integrate extant data for population-based health purposes; and 2) teach practitioners how to use data for program planning, policy development, and evaluation, making use of current information resources.^{8(p3)}

This led to an effort to identify, document, and describe exemplary state and local integrated public health information systems.

As a first step, it was important to establish criteria for determining what constitutes an "exemplary" practice. This involved input from experts in the public health practice and research communities. Once the criteria were established, literature was reviewed, and Internet searches were conducted in an attempt to identify and locate potential exemplary practices. In addition, those involved in the development and/or use of such systems were queried about the existence of potential exemplary systems. Through reviews of the literature, descriptions of systems, and interviews of individuals involved in developing and running these systems, approximately 20 exemplary practices have been identified to date. Following this identification, information from these systems is analyzed and synthesized. Common characteristics and lessons learned in development, use, and maintenance of these systems are being culled to provide quality summary information to those who are interested in learning from these current practices. In addition, descriptions of each exemplary practice, as well as the "lessons learned," are being prepared for posting on the Internet and for incorporation into curricula for distance learning geared to practicing public health professionals. While less rigorous scientifically than some of the efforts mentioned above, this type of information development and dissemination clearly can help the public health community learn from those in the community about building better public health programs.

Finally, there is a need for new sources of primary data and information that enable us to better measure public health practices and accomplishments. It is not uncommon for organizations to do, for the most part, what they can measure. This being the case, it is important that we measure what is relevant for meeting community health needs.

For example, the majority of states established health objectives for the year 2000. Approximately three-fourths of these states indicated that the availability of data influenced the selection of their health objectives. Many states lacked objectives in areas of mental health, occupational health, and substance abuse, not because there are no problems in these areas, but because they lacked baseline data. It is important to have accurate and reliable information in these areas because many requests for resources and development of targeted health promotion campaigns are linked strongly to having established health objectives.⁹

While it is evident that new primary data and information sources may be necessary for the appropriate targeting of community public health programs, it is equally important to consider what data currently being collected are not being used. Substantial reporting burdens are placed on our nation's state and local public health agencies. It is highly conceivable that new data sources can

be added to address identified needs, while at the same time removing some existing reporting burdens when there is little demonstrated use for the data. As indicated throughout this report, resources are extremely limited for creating and maintaining high-quality public health information. We must, therefore, learn to establish priorities for our needs, remove what is not useful, and create new sources of information to meet identified needs when quality information does not currently exist.

CONCLUSION

There is high-quality information in public health that can, and should, be used for developing, implementing, and evaluating public health policies and programs. Problems often exist in finding this quality information or the data that can be used for its development. Even when the information may exist, it is not always accessed or recognized for its potential usefulness. Training individuals on how to access information, to assess quality, and to use information that already is available is crucial. In addition, investing in the cataloging of quality information and in establishing "authoritative" sources of quality information can increase substantially the use of data for public health policies and programs.

There also remains the need to develop new public health information sources, particularly in the areas of infrastructure and best practices. More complete and higher-quality information in these areas will lead to the development of better tools for enabling our public health system to operate more efficiently and effectively.

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